

***Appendix B: Key Results from the Family Health Survey
and CSHCN Survey***

Family Health Survey
Questions 14, 17, 23, 24, 27

| Question 14: When living in Idaho, when you or your partner were pregnant did you ever need help with... | | | | | | | | | | | | |
|--|----------|-------|-----------------------|------|----------------------|------|---------------------------|------|---|------|---|-------|
| Service | | | Yes, needed help..... | | | | | | | | | |
| | | | No, did not need help | | But didn't seek help | | Looked, but couldn't find | | Found people and/or information but never used it | | Found people and/or information to assist, but it was not helpful | |
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| Finding prenatal care | 269 | 57.6% | 3 | 0.6% | 5 | 1.1% | 0 | 0% | 8 | 1.7% | 182 | 39.0% |
| Paying for prenatal care | 162 | 34.9% | 24 | 5.2% | 9 | 1.9% | 3 | 0.7% | 20 | 4.3% | 246 | 53.0% |
| What to expect regarding pregnancy and child birth | 194 | 42.0% | 5 | 1.1% | 2 | 0.4% | 3 | 0.7% | 19 | 4.1% | 239 | 51.7% |
| Advice on healthy eating | 190 | 41.0% | 13 | 2.8% | 5 | 1.1% | 8 | 1.7% | 15 | 3.2% | 233 | 50.2% |
| Information on what to do once the baby arrives | 194 | 42.2% | 8 | 1.7% | 7 | 1.5% | 4 | 0.9% | 20 | 4.4% | 227 | 49.4% |
| Worries about whether the baby would be born healthy | 214 | 46.7% | 6 | 1.3% | 5 | 1.1% | 3 | 0.7% | 12 | 2.6% | 218 | 47.6% |
| Alcohol or drug use | 414 | 90.2% | 4 | 0.9% | | | 2 | 0.4% | 3 | 0.7% | 36 | 47.6% |
| Quitting smoking | 385 | 84.4% | 13 | 2.9% | 3 | 0.7% | 8 | 1.8% | 11 | 2.4% | 36 | 7.9% |
| Feeling depressed or nervous | 294 | 64.2% | 44 | 9.6% | 13 | 2.8% | 8 | 1.8% | 15 | 3.3% | 84 | 18.3% |

| Question 17: While living in Idaho, When you had an infant (birth to one year old) did you or your partner ever need help with . . . | | | | | | | | | | | | |
|--|-----------------------|-------|-----------------------|--------|---------------------------|------|---|------|---|------|--|-------|
| Service | No, did not need help | | Yes, needed help..... | | | | | | | | | |
| | | | But didn't seek help | | Looked, but couldn't find | | Found people and/or information but never used it | | Found people and/or information to assist, but it was not helpful | | Found people and/or information to assist and it was helpful | |
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| Finding a doctor for your infant | 267 | 57.4% | 3 | 0.7% | 4 | 0.9% | 3 | 0.7% | 10 | 2.2% | 178 | 38.3% |
| Paying for a doctor for your infant | 192 | 41.2% | 16 | 3.4% | 10 | 2.2% | 2 | 0.4% | 16 | 3.4% | 230 | 49.4% |
| Finding someone to take care of your baby while you worked or went to school | 249 | 53.6% | 13 | 2.8% | 37 | 8.0% | 4 | 0.9% | 33 | 7.1% | 129 | 27.7% |
| Breastfeeding | 233 | 50.4% | 8 | 1.7% | 6 | 1.3% | 8 | 1.7% | 32 | 6.9% | 175 | 37.9% |
| Feeling sad, blue, or depressed | 261 | 56.9% | 47 | 10.2 % | 17 | 3.7% | 7 | 1.5% | 17 | 3.7% | 110 | 24.0% |
| Feeling overwhelmed | 241 | 52.4% | 58 | 12.6 % | 20 | 4.4% | 6 | 1.3% | 60 | 4.4% | 115 | 25.0% |
| Concerns that your baby was not growing or developing like he or she was supposed to | 312 | 67.4% | 3 | 0.7% | 6 | 1.3% | 2 | 0.4% | 6 | 1.3% | 134 | 28.9% |

| Question 20: While living in Idaho, when you had a young child (ages 1 to 12 years old) did you ever need help with. . . | | | | | | | | | | | | |
|---|-----------------------|-------|-----------------------|------|---------------------------|------|---|-------|---|------|--|-------|
| Service | No, did not need help | | Yes, needed help..... | | | | | | | | | |
| | | | But didn't seek help | | Looked, but couldn't find | | Found people and/or information but never used it | | Found people and/or information to assist, but it was not helpful | | Found people and/or information to assist and it was helpful | |
| | n | % | n | % | n | % | n | % | n | % | n | % |
| Finding a doctor for your child | 302 | 59.9% | 8 | 1.6% | 8 | 1.6% | 2 | 0.4% | 13 | 2.6% | 171 | 33.9% |
| Finding a dentist for your child | 255 | 51.3% | 21 | 4.2% | 31 | 6.2% | 6 | 1.2% | 26 | 5.2% | 158 | 31.8% |
| Finding someone to take care of your baby while you worked or went to school | 272 | 54.5% | 19 | 3.8% | 38 | 7.6% | 8 | 1.6% | 32 | 6.4% | 130 | 26.1% |
| Advice on making sure your child was eating right | 275 | 55.2% | 5 | 1.0% | 5 | 1.0% | 6 | 1.2% | 11 | 2.2% | 196 | 39.4% |
| Concerns that your child felt sad, blue, or depressed more than he or she should | 383 | 76.8% | 13 | 2.6% | 9 | 1.8% | 5 | 1.0% | 13 | 2.6% | 76 | 15.2% |
| Using appropriate discipline with your child | 323 | 64.9% | 18 | 3.6% | 15 | 3.0% | 7 | 1.4% | 5 | 1.0% | 130 | 15.2% |
| Concerns that your child was not growing or developing like he or she was supposed to | 349 | 69.5% | 6 | 1.2% | 5 | 1.0% | 3 | 0.6% | 8 | 1.6% | 128 | 25.7% |
| Concerns that you child could not sit still, focus on directions, or concentrate as well as other children his or her age | 360 | 72.1% | 14 | 2.8% | 13 | 2.6% | 3 | 60.0% | 13 | 2.6% | 96 | 19.2% |
| Concerns that your child was overweight | 432 | 72.1% | 9 | 1.8% | 5 | 1.0% | 3 | 0.6% | 14 | 2.8% | 35 | 7.0% |

| Question 23: While you were living in Idaho when you had a teenager (ages 13 to 19 years old) did you ever need help with . . . | | | | | | | | | | | | |
|---|----------|-------|-----------------------|-------|----------------------|------|---------------------------|------|---|---|--|-------|
| Service | | | Yes, needed help..... | | | | | | | | | |
| | | | No, did not need help | | But didn't seek help | | Looked, but couldn't find | | Found people and/or information but never used it | Found people and/or information to assist, but it was not helpful | Found people and/or information to assist and it was helpful | |
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| Finding a doctor for your teenager | 109 | 65.7% | 3 | 1.8% | 3 | 1.8% | 3 | 1.8% | 7 | 4.2% | 41 | 24.7% |
| Paying for a doctor for your teenager | 82 | 50.3% | 18 | 11.0% | 6 | 3.7% | 2 | 1.2% | 10 | 6.1% | 45 | 27.6% |
| Finding a dentist for your teenager | 94 | 58.0% | 4 | 2.5% | 13 | 8.0% | 1 | 0.6% | 12 | 7.4% | 38 | 23.5% |
| Concerns that your teenager was overweight | 121 | 73.8% | 15 | 9.2% | 3 | 1.8% | 3 | 1.8% | 3 | 1.8% | 19 | 11.6% |
| Using appropriate discipline with your teenager | 109 | 65.7% | 12 | 7.2% | 6 | 3.6% | 1 | 0.6% | 10 | 6.0% | 28 | 16.9% |
| Concerns that your teenager felt sad, blue or depressed more than he or she should | 98 | 59.4% | 7 | 4.2% | 6 | 3.6% | 3 | 1.8% | 14 | 8.5% | 37 | 22.4% |
| Concerns that your teenager was lonely, socially immature or having trouble making friends | 113 | 68.5% | 11 | 6.7% | 11 | 6.7% | 2 | 1.2% | 11 | 6.7% | 17 | 10.3% |
| Concerns that your teenager was using drugs or alcohol | 132 | 80.0% | 3 | 1.8% | 3 | 1.8% | 1 | 0.6% | 12 | 7.3% | 14 | 8.5% |

| Question 23: While you were living in Idaho when you had a teenager (ages 13 to 19 years old) did you ever need help with . . . | | | | | | | | | | | | |
|---|-----------------------|-------|-----------------------|------|---------------------------|------|---|------|---|-------|--|-------|
| Service | No, did not need help | | Yes, needed help..... | | | | | | | | | |
| | | | But didn't seek help | | Looked, but couldn't find | | Found people and/or information but never used it | | Found people and/or information to assist, but it was not helpful | | Found people and/or information to assist and it was helpful | |
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| Concerns that your teenager was not doing well in school | 100 | 60.6% | 9 | 5.5% | 6 | 3.6% | 2 | 1.2% | 22 | 13.3% | 26 | 15.8% |
| Concerns that your teenager could not sit still, focus on directions, or concentrate as well as other children his or her age | 128 | 77.6% | 3 | 1.8% | 1 | 0.6% | 1 | 0.6% | 13 | 7.9% | 19 | 11.5% |
| Concerns about whether your teenager was having sex | 130 | 78.8% | 7 | 4.2% | 2 | 1.2% | 2 | 1.2% | 10 | 6.1% | 14 | 8.5% |
| Concerns that your teenager may harm themselves | 134 | 82.2% | 4 | 2.5% | 2 | 1.2% | 1 | 0.6% | 8 | 4.9% | 14 | 8.6% |
| Concerns that your teenager may be physically or verbally abusive | 138 | 84.2% | 6 | 3.7% | 3 | 1.8% | 2 | 1.2% | 5 | 3.1% | 10 | 6.1% |

| Question 24: While residing in Idaho, and within the last 5 years, has anyone in your household ever needed help with any of the following . . . | | | | | | | | | | | | |
|--|-----------------------|-------|----------------------|------|---------------------------|------|---|------|---|------|--|-------|
| Service | Yes, needed help..... | | | | | | | | | | | |
| | No, did not need help | | But didn't seek help | | Looked, but couldn't find | | Found people and/or information but never used it | | Found people and/or information to assist, but it was not helpful | | Found people and/or information to assist and it was helpful | |
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| Concerns over feeling sad, blue or depressed | 327 | 54.1% | 56 | 9.3% | 20 | 3.3% | 11 | 1.8% | 28 | 4.5% | 162 | 26.8% |
| Concerns that someone may harm themselves | 529 | 87.9% | 13 | 2.2% | 4 | 0.7% | 1 | 0.2% | 13 | 2.2% | 42 | 7.0% |
| Concerns that someone may be physically or verbally abusive to others | 522 | 86.9% | 24 | 4.0% | 7 | 1.2% | 2 | 0.3% | 9 | 1.5% | 37 | 6.2% |
| Information on how to obtain public assistance such as food stamps, cash assistance, or emergency assistance programs | 337 | 56.1% | 12 | 2.0% | 17 | 2.8% | 6 | 1.0% | 32 | 5.3% | 197 | 32.8% |
| Family planning or birth control advice | 408 | 68.3% | 12 | 2.0% | 2 | 0.3% | 3 | 0.5% | 12 | 2.0% | 160 | 26.8% |
| Concerns over alcohol or drug abuse | 530 | 89.1% | 18 | 3.0% | 6 | 1.0% | 6 | 1.0% | 11 | 1.9% | 24 | 4.0% |

| Question 27: Experience using Idaho CareLine | | | | | | | | | | |
|--|----------------|-------|----------------|-------|----------------------------|-------|-------------------|-------|-------------------|-------|
| | Strongly Agree | | Somewhat Agree | | Neither Agree nor Disagree | | Somewhat Disagree | | Strongly Disagree | |
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| It has been helpful | 75 | 47.2% | 44 | 27.7% | 22 | 13.8% | 9 | 5.7% | 9 | 5.7% |
| It provided resources that were accessible to someone living in my area of Idaho | 70 | 46.1% | 47 | 30.9% | 18 | 11.8% | 10 | 6.6% | 7 | 4.6% |
| I was not eligible for the help that I was referred to | 33 | 22.2% | 17 | 11.4% | 56 | 37.6% | 15 | 10.1% | 28 | 18.8% |
| The help that was offered addressed the problem I called the CareLine for | 63 | 41.2% | 42 | 27.5% | 28 | 18.3% | 9 | 5.9% | 11 | 7.2% |

Idaho Families of Children With Special Health Care Needs Survey

Questions 7_1, 7_2, 8, 11

| Question #7_1: Please indicate how much information you currently have in each area and how important you think this information is for families of children with special health care needs | | | | | | |
|---|---|-------|-------------------------|-------|----------------------------|-------|
| Type of Information | How Much information do you have on this topic? | | | | | |
| | Have Enough Information | | Have Some but Need More | | Need Much More Information | |
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| What care coordinator services are available to my family | 59 | 54.1% | 31 | 28.4% | 19 | 17.4% |
| How to get care coordination services | 56 | 51.4% | 34 | 31.2% | 19 | 17.4% |
| All health and support services available to families of children with special needs | 41 | 37.6% | 48 | 44.0% | 20 | 18.4% |
| How to apply for Medicaid | 83 | 76.9% | 11 | 10.2% | 14 | 13.0% |
| Information about the services covered by Medicaid | 47 | 43.1% | 38 | 34.9% | 24 | 22.0% |
| Information about Katie Beckett health coverage | 30 | 28.9% | 13 | 12.5% | 61 | 58.7% |
| Information about applying for SSI or other disability benefits | 55 | 51.4% | 26 | 24.3% | 26 | 24.3% |
| What services are available to prepare for my child's transition to adulthood | 27 | 25.5% | 27 | 25.5% | 52 | 49.1% |
| What needs to be done to keep Medicaid eligibility | 45 | 42.1% | 32 | 29.9% | 30 | 28.0% |
| Information about parent support groups in my area | 45 | 41.7% | 29 | 26.9% | 34 | 31.5% |
| Information about parent support groups around the country | 45 | 41.7% | 32 | 29.6% | 31 | 28.7% |

Question #7_2: Please indicate how much information you currently have in each area and how important you think this information is for families of children with special health care needs?

| Type of Information | How important is it for families of children with special needs to have information on this topic | | | | | |
|--|---|-------|--------------------|-------|---------------|-------|
| | Very Important | | Somewhat Important | | Not Important | |
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| What care coordinator services are available to my family | 100 | 91.7% | 8 | 7.3% | 1 | 0.9% |
| How to get care coordination services | 100 | 92.6% | 8 | 7.4% | | |
| All health and support services available to families of children with special needs | 106 | 97.3% | 2 | 1.8% | 1 | 0.9% |
| How to apply for Medicaid | 100 | 92.6% | 5 | 4.6% | 3 | 2.8% |
| Information about the services covered by Medicaid | 100 | 91.7% | 8 | 7.3% | 1 | 0.9% |
| Information about Katie Beckett health coverage | 84 | 81.6% | 15 | 14.6% | 4 | 3.9% |
| Information about applying for SSI or other disability benefits | 93 | 87.5% | 10 | 9.4% | 3 | 2.8% |
| What services are available to prepare for my child's transition to adulthood | 90 | 83.3% | 15 | 13.9% | 3 | 2.8% |
| What needs to be done to keep Medicaid eligibility | 95 | 87.2% | 8 | 7.3% | 6 | 5.5% |
| Information about parent support groups in my area | 80 | 73.4% | 23 | 21.1% | 6 | 5.5% |
| Information about parent support groups around the country | 63 | 58.3% | 33 | 30.6% | 12 | 11.1% |

| Question #8: Please indicate how effective you think is each of the following ways of sharing information with families of children with special needs. | | | | | | |
|---|--|-------|--------------------|-------|---------------|-------|
| Possible Ways to Obtain Information | How effective do you think it is . . . | | | | | |
| | Very Effective | | Somewhat Effective | | Not Effective | |
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| From a brochure or pamphlet | 32 | 29.1% | 74 | 67.3% | 4 | 3.6% |
| From a care coordinator | 87 | 79.1% | 21 | 19.1% | 2 | 1.8% |
| At a community meeting | 27 | 25.0% | 63 | 58.3% | 18 | 16.7% |
| From parent support groups | 60 | 55.1% | 40 | 36.7% | 9 | 8.3% |
| Have the local health department provide the information | 50 | 46.3% | 48 | 44.4% | 10 | 9.3% |
| Through hospitals | 57 | 52.3% | 43 | 39.5% | 9 | 8.3% |
| Over the Internet | 54 | 50.0% | 41 | 38.0% | 13 | 12.0% |
| Call an 800 number | 26 | 24.5% | 57 | 53.8% | 23 | 21.7% |
| Other-Please describe | 9 | 60.0% | 3 | 20.0% | 3 | 20.0% |

| Question #11: How important are the following care coordination services to you, your child and your family? | | | | | | |
|--|--|-------|--------------------|-------|---------------|-------|
| | How important do you think it is . . . | | | | | |
| | Very Important | | Somewhat Important | | Not Important | |
| | <i>n</i> | % | <i>n</i> | % | <i>n</i> | % |
| Medical and Support Services Coordination | | | | | | |
| Coordination of child's medical care (doctor and hospital visits) | 84 | 77.1% | 11 | 10.1% | 14 | 12.8% |
| Coordination of communication between doctors, hospital, and therapists | 93 | 85.3% | 10 | 9.2% | 6 | 5.5% |
| Coordination of therapies | 91 | 84.3% | 8 | 7.4% | 9 | 8.3% |
| Assistance applying for Medicaid | 76 | 70.4% | 23 | 21.3% | 9 | 8.3% |
| Assistance keeping Medicaid coverage | 78 | 72.2% | 22 | 20.4% | 8 | 7.4% |
| Assistance managing family finances | 45 | 42.1% | 37 | 34.6% | 25 | 23.4% |
| Assistance applying for Katie Beckett health coverage | 70 | 68.6% | 20 | 19.6% | 12 | 11.8% |
| Coordination of child's insurance coverage | 80 | 74.8% | 20 | 18.7% | 7 | 6.5% |
| Access to ongoing up-to-date information about programs, services, and eligibility changes | 101 | 92.7% | 8 | 7.3% | | |
| Assistance locating local parent support groups or parent support network | 60 | 55.6% | 40 | 37.0% | 8 | 7.4% |
| Assistance locating out-of-state parent support groups or parent support network | 39 | 36.1% | 42 | 38.9% | 27 | 25.0% |
| Education Services Coordination | | | | | | |
| Understanding what is required of schools in regard to IEPs (Individual Education Plans) | 90 | 83.3% | 15 | 13.9% | 3 | 2.8% |
| Assisting with development of child's IEP | 89 | 83.2% | 13 | 12.2% | 5 | 4.7% |
| Assisting with coordinating IEP | 86 | 80.4% | 16 | 15.0% | 5 | 4.7% |
| Coordinating child's physical care while at school | 86 | 81.9% | 15 | 14.3% | 4 | 3.8% |
| Assistance accessing testing | 86 | 81.1% | 15 | 14.2% | 5 | 4.7% |
| Assistance accessing and using therapies | 88 | 83.8% | 15 | 14.3% | 2 | 1.9% |
| Understanding what is required of schools under special education laws and regulations | 93 | 86.9% | 12 | 11.2% | 2 | 1.9% |